

Fetal Alcohol Spectrum Disorder (FASD) ~ 2008-2009

Background:

Most of us know someone, or have encountered someone, who has most likely been damaged by prenatal alcohol exposure. These are the homeless people we see wandering the streets, they are the teens who have been incarcerated for the better part of their youth, they are the adults who are labeled chronic repeat offenders and spend the better part of their lives in jail or prison (where they are often model prisoners because they thrive on the structure and supervision they receive while incarcerated). These are the people who receive services from various state or local agencies but who regularly fail or are dismissed from these programs due to “non-compliance” or “resistance”. The lack of follow through, the seeming lack of motivation, the lack of understanding of cause and effect, the poor judgment, the chronic lack of overall success or “improvement” in these people’s lives goes unrecognized for what it is----- **brain damage caused by prenatal exposure to alcohol**. This disability is 100% preventable and yet no real effort is being made in Connecticut to prevent it. The individuals affected by this “invisible” disability do not have the support, education, or proper treatment that they require to be successful in their lives. The cycle will continue unless a concerted, statewide effort is made to address it. (Michelle Bidwell, President NOFAS CT 2008)

Proposal ~ Next Steps:

- Mandate at least two state agencies to co-lead a statewide Task Force (DCF & DMHAS are probably the most impacted by this issue although could also be, or include, DDS, DPH, CSSD, DSS, BRSS, Juvenile Justice, Dept. of Corrections). Need at least two co-leads for this effort to ensure a collaborative effort to identify needs, develop, and implement a statewide system of care or “best practices” model.
- Get commitment from Commissioners of state agencies to put FASD efforts on the agenda and to dedicate resources (staff, time, funding) to this effort. This will ensure sustainability and accountability of the Task Force.
- Task Force members should consistently include identified stakeholders at the state level but should also include a varied cohort of community agencies and consumers (e.g. Birth to Three, The ARC, United Services, Casey Family Services, women’s treatment providers, medical and mental health providers, UCEDD, birth, adoptive, and foster families).
- Determine the focus and mission of the Task Force: prevention, identification and diagnosis, dissemination of information/education, treatment/intervention, all? Breakout to appointed committees to address various separate areas and issues then bring all data & info together in full Task Force meetings?
- Develop a needs analysis survey----poll physicians, mental health providers, other treatment providers (substance abuse, women’s health/mental health), educators, parents (birth, adoptive, foster)---- to determine the extent of this problem, the unmet needs of the FASD population (including proper diagnosis, effective treatment, support, education), the needs of the community providers and families (education, support, referral, other).

- Develop short and long-term Goals and Objectives for the Task Force efforts. Identify a model to document ongoing efforts and progress, a timeline, and a process for (annually?) reporting Task Force efforts and progress to the Governor, Commissioners, and the public.
- Consider that diagnosis of a Fetal Alcohol Spectrum Disorder (FAS, FAE, ARND, ARBD, p-FAS) should be a diagnosis that is reportable to the Dept. of Public Health (regardless of the age at diagnosis, not just reported at birth). This would ensure more accurate assessment of the scope of this problem.
- Request TA from the New Jersey Regional FASD Diagnostic Centers, Dr. Susan Adubato, for assistance in developing a **statewide FASD initiative**. It also may be possible to obtain some TA from the SAMHSA FASD Center for Excellence. Dedicate some member(s) of the Task Force to identifying possible funding sources (federal, state, grants, private, corporate).
- Plan and implement a Statewide FASD Conference with a target audience of staff from state agencies (DCF, Juvenile Justice, CSDE, etc), medical, mental health, community providers, and parents. Model this conference after others that have been done in other states----include speakers (national FASD experts, researchers, educators), include workshops/workgroups, include opportunities for networking between/among participants.
- Develop a pilot FASD Diagnostic Center program. Identify and train a multidisciplinary staff (psychiatrist, developmental pediatrician, psychologist, speech & language pathologist, occupational therapist, others?). Training in diagnosing FASD can be obtained from various sources including the New Jersey Regional Diagnostic Centers. Various models/similar programs have been used in other states and would serve as appropriate models for this program. Actively seek funding (federal, grant, private, corporate) to support this effort.
- Develop a website for the Connecticut FASD Task Force that includes information about FASD, information about FASD in Connecticut, resources and referral information, and regular updates on the efforts and progress of the task force.

Who are the people affected by FASD?

These are the children in the foster care system (as many as 75% of this population) that gets bounced from foster home to foster home because no one can manage their behaviors and their caregivers get “burned out”.

These are the children of middle or upper middle class families where the mother consumed alcohol during pregnancy but the children are never labeled with FASD. They struggle in school, have behavior issues at home, and are diagnosed as severely learning disabled or with a conduct disorder. These children are sent away to boarding schools by their affluent families and often end up as the “black sheep of the family” who, as an adult is often jobless, homeless, in trouble with the law, and has ongoing mental health and substance abuse issues.

These are the children who struggle in school in spite of having normal IQ's. After awhile, when none of the teaching strategies that are tried are working, these are the kids who are labeled as "behavior problems" and written off as incorrigible by school staff.

These are the kids who become behavior problems because they cannot live up to the high expectations of their families, schools and communities. They begin by acting out in school, move on to truancy, and eventually drop out of school.

These are the kids who are highly vulnerable to peer pressure and often end up getting into drugs, alcohol, and petty crime. Their social skills are often not good and they gravitate to the only crowd of peers who will accept them---other kids who are involved in drugs, alcohol, and crime. These kids are real "followers" and thrive in situations when someone else is directing their thoughts and activities, even if those activities are not socially acceptable or even legal!

These are the kids who are involved with the juvenile justice system at an early age and are often "repeat offenders" throughout their lives.

These are the kids who end up in residential placements because their behaviors are out of control and they often continue to carry the label of "behavior disordered".

These kids often, by late adolescence, carry many mental health diagnoses: mood disorders, ADHD, ODD, OCD, PDD, intermittent explosive disorder, conduct disorder, borderline personality disorder. Only about 25 % will ever be diagnosed with FASD.

These are the kids who, by early adulthood, are unable to maintain a job, are frequently homeless, appear to have no skills in money management (spend it as fast as they make it, unable to pay bills, etc) and continue to have ongoing mental health and substance abuse issues..

As young adults with mental health diagnoses, these people sometimes qualify for services from state or community agencies. They very often fail in these services or programs and are described as "non-compliant" or "resistant" to treatment. The reality is that their brain damage causes them to be disorganized, not understand cause and effect, be impulsive, have poor judgment, and not have the cognitive or emotional resources to succeed without support.

These are the people who have children but are unable to successfully raise them. They are often accused of being neglectful, sometime abusive, and are unfit to parent. Their children are often raised by family members or enter foster care. The biological family is often dysfunctional due to ongoing substance abuse issues, chronic unemployment, homelessness, joblessness, domestic violence and is unable to reunify with their children.

Their children, who were conceived by mothers with unrecognized brain damage caused by prenatal alcohol exposure and long-standing histories of their own substance abuse issues, are also born with this same brain damage and the cycle begins again.